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Families' experiences of intensive care unit quality of care: Development and validation of a European questionnaire (euroQ2)[☆]



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ABSTRACT

Purpose: The purpose of the study is to adapt and provide preliminary validation for questionnaires evaluating families' experiences of quality of care for critically ill patients in the intensive care unit (ICU).

Materials and methods: This study took place in 2 European ICUs. Based on literature and qualitative interviews, we adapted 2 previously validated North American questionnaires: "Family Satisfaction with the ICU" and "Quality of Dying and Death." Family members were asked to assess relevance and understandability of each question. Validation also included test-retest reliability and construct validity.

Results: A total of 110 family members participated. Response rate was 87%. For all questions, a median of 97% (94%–99%) was assessed as relevant, and a median of 98% (97%–100%), as understandable. Median ceiling effect was 41% (30%–47%). There was a median of 0% missing data (0%–1%). Test-retest reliability showed a median weighted κ of 0.69 (0.53–0.83). Validation showed significant correlation between total scores and key questions.

Conclusions: The questions were assessed as relevant and understandable, providing high face and content validity. Ceiling effects were comparable to similar instruments; missing data, low; and test-retest reliability, acceptable. These measures are promising for use in research, but further validation is needed before they can be recommended for routine clinical use.

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1. Introduction

Most patients admitted to intensive care unit (ICU) are critically ill, and 10% to 15% of the patients die in the unit [1,2]. For health care professionals, the high-technology environment becomes commonplace, but for families, this is a new and uncertain world [3]. Families often see their role as guardian and protector of the patient, but they also have needs of their own. They need support to cope with the uncertainty and need complete information to be able to understand what is going on and how to navigate in the ICU [4]. The strains experienced by families during an ICU stay may subsequently lead to posttraumatic stress syndrome and depression [5–8]. Care that also takes the needs of families

into account is, therefore, very important, but to be able to offer family-centered care, it is necessary to understand families' experiences [9].

A Canadian questionnaire (Family Satisfaction in the Intensive Care Unit [FS-ICU]), which examines families' general satisfaction with intensive care [9,10], and an American questionnaire, which examines families' rating of the quality of dying and death (QODD) [11,12], have been developed and validated. The QODD questionnaire has been used in a Dutch study [13], but a high percentage of nonrelevant or missing responses suggested that the questionnaire is not automatically transferable to European ICU environments.

The overall goal of this study was to adapt and validate questionnaires to evaluate families' experiences of quality of care for critically ill and dying patients in the ICU based on the FS-ICU and the QODD and adapted to Northern European environments. The questionnaires, including both a European FS-ICU and a European QODD, were named "euroQ2" (European Quality Questionnaire). Our specific aims were to (a) pilot test the instrument with family members, intensivists, ICU nurses, and questionnaire experts and then (b) examine the responses from family members of patients in the ICU to assess the distribution of response, the proportion of missing values, the content validity, and the construct validity of the euroQ2.

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2. Materials and methods

The euroQ2 incorporates issues identified as the most important by family members as well as an opportunity to add qualitative comments about issues not addressed in the questionnaire. The euroQ2 consists of 2 components: satisfaction with care measured with the adapted FS-ICU for family members of all patients in the ICU and quality of dying and death measured with the adapted QODD for family members of patients who died in the ICU. The adapted questionnaires will be referred to as euroFS-ICU and euroQODD, respectively.

2.1. Setting

The study took place in 2 ICUs. The Danish ICU was a general ICU from a 300-bed regional hospital with 8 ICU beds and receives mainly patients from medical and surgical specialities. The Dutch ICU was a medical-surgical ICU from an 800-bed university-affiliated hospital with 22 ICU beds and admits surgical, trauma, medical, and cardiothoracic patients.

2.2. Study design

The study included a pilot test phase and a validation phase. Before pilot testing, we adapted the FS-ICU and QODD based on results from the Dutch prestudy [13]; results from serial, semistructured interviews with 8 family members of Danish ICU patients; and previously published research on the experiences of the family of critically ill patients. This adaptation phase was conducted from January to August 2013 and resulted in an initial draft of the euroQ2 in English. An overview of the adaptations can be found as supplementary material.

2.3. Inclusion criteria

We included family members of patients admitted to the ICU for 48 hours or more. Up to 3 family members per patient could participate. Family members were defined as the persons closest to the patient (as defined by the patient), including partners, siblings, children, parents, and friends. If there were more than 3 family members who wanted to participate, the family members themselves decided who it should be based on who had spent most time in the ICU.

2.4. Exclusion criteria

The following are exclusion criteria: family members younger than 18 years, family members with cognitive impairment, and family members not able to read or write Danish or Dutch.

2.5. Pilot testing phase

The initial draft of euroQ2 was reviewed by 2 family members, 5 nurses, 4 intensivists, and 2 questionnaire experts from both Denmark and The Netherlands. For each item, feedback was obtained about the clarity, relevance, and acceptability (is the question phrased in an acceptable way or is it, for example, condescending or value laden). After adjustments (please see [Supplementary material](#) for details) based on the feedback, the final draft was discussed with and approved by 1 of the developers of the FS-ICU and QODD (JRC) and then translated into Danish and Dutch. In both countries, the translation process consisted of 2-way translations (the questionnaire was translated from English to Danish [and likewise to Dutch] by 2 persons fluent in both languages and then back from Danish by 2 others fluent in both languages but without knowledge of the original English version), discussion of the different versions in a research group, and consensus decision on which phrasings were correct in Danish (and likewise in Dutch). The questionnaire was then evaluated qualitatively in both Denmark and The Netherlands by family members (6 from each country). The family members filled in the questionnaire, assessed for each question whether they found it relevant

and/or understandable, and were interviewed subsequently about their overall assessment of the questionnaire: if there were important areas missing, if the information was adequate, and how they understood each question. After the pilot testing phase, the euroFS-ICU consisted of 20 questions and 2 options for providing comments (compared to 27 questions and 3 options to provide comments in the FS-ICU) [9]. Ten of the questions were identical, 5 were partially different, and 5 were completely different from the FS-ICU. The euroQODD consisted of 15 questions and 1 option for providing comments (compared to 47 questions in the QODD) [11]. Six questions were almost identical; the others were different from the QODD. The pilot testing phase was conducted from February to November 2013. A copy of the euroQ2 (euroFS-ICU and euroQODD) is available as [Supplementary material](#).

2.6. Validation phase

The aim of this phase was to quantitatively validate the euroQ2 in regard to distribution of responses, the proportion of missing values, the content validity (do the questionnaires reflect the areas that are essential to clarify the purpose of the questionnaires), and the construct validity (the extent to which the questionnaires measure the expected concepts) of the 2 measures. In this phase, 55 family members from the Danish ICU and 55 family members from the Dutch ICU participated. As in the pilot testing phase, the participants were asked to assess relevance and understandability for each question. They also filled in the Hospital Anxiety and Depression Scale (HADS) [14] and the revised Impact of Event Scale (IES-R) [15]. There already existed validated Danish and Dutch versions of the HADS and a Dutch version of the IES-R. A 2-way translation with consensus discussion (as described above) was conducted for a Danish IES-R version. While still at the ICU, the families were asked by the patients' nurse or physician whether they wanted to take part in the study and were provided with written information (please see [Supplementary material](#)). If the family members agreed to participate, they were asked to fill in a form with name, address, and telephone number. Three weeks after the patient either died or was discharged from the ICU, the questionnaire (together with an accompanying letter and a prepaid envelope) was mailed to family members. If the questionnaire was not returned after 2 weeks, the participants were contacted by telephone and asked to return the questionnaire. All returned questionnaires were included in the analyses independently of when they were returned. To get an indication of test-retest reliability, questionnaires were sent 2 weeks after a questionnaire was returned until 10 completed questionnaires were collected in each country. For the participating families, the following patient data were obtained from the medical record: sex, age, medical or surgical speciality of the admitting physician, diagnosis, length of stay in the ICU, any withholding or withdrawal decisions, Acute Physiology and Chronic Health Evaluation II (APACHE II) [16], Simplified Acute Physiology Score (SAPS) [17], and Sepsis-Related Organ Failure Assessment (SOFA) scores [18]. The validation phase was conducted from December 2013 to July 2014.

2.7. Scoring

For correlation analyses, Likert scale responses in the euroFS-ICU were transformed to a 0–100 scale according to the FS-ICU scoring [9,10], and 1 single question “When major decisions were made, did you have adequate time to have your concerns addressed and questions answered?” was transformed as 100 for yes and 0 for no. A total score for the euroFS-ICU was calculated as means of individual item scores provided that the respondents had answered more than 70% of the items included [9]. The euroQODD consists of more diverse response categories, and therefore, correlation analyses were based on a single item response of overall assessment of care (scale from 0 to 10) transformed to a 0–100 scale and a key question: “End-of-life care according to wishes.” For this question, response options were “yes,” “partially,” “no,” and “don't know,” and the responses were scored as 100 for yes, 50 for partially, and 0 for no.

Hospital Anxiety and Depression Scale scores were divided into 4 categories: none (0–7), mild (8–10), moderate (11–15), and serious (≥ 16) [14], and the IES-R scores, into averages of 3 domains (intrusion, avoidance, and hyperarousal) on a scale from 0 to 4, where 4 is the worst possible. The IES-R has no cutoff points [15].

2.8. Data analyses

Statistical analyses were conducted using Stata 13 and SPSS 18. For comparing background characteristics of Danish and Dutch family members and patient data, we used the Student *t* test, χ^2 or Fisher exact test, or Mann-Whitney *U* test, as appropriate. Descriptive statistics were used to present distribution of responses, proportion of missing data, and content validity. Weighted κ was used for test-retest reliability analysis. Total score of the euroFS-ICU and single item overall care score from the euroQODD were not normally distributed. Correlation analyses were, therefore, conducted based on the nonparametric Spearman rank correlation coefficients. Cluster effect was checked by conducting Spearman rank correlation analyses with 1 family member per patient and with Pearson correlation with cluster option (adjusting for ≥ 1 family member per patient). Based on FS-ICU and QODD literature [9,12], we hypothesized that higher total euroFS-ICU score would correlate with higher scores on 2 key questions (concern and caring by ICU staff and overall quality of information). For the euroQODD, we hypothesized a higher score of overall assessment of care would correlate with higher scores of key question (end-of-life care according to wishes) and with higher total euroFS-ICU score. Furthermore, we hypothesized that higher total euroFS-ICU scores and higher euroQODD overall care score would correlate with lower levels of anxiety, depression, and posttraumatic stress symptoms. $P < .05$ was considered significant for all analyses.

2.9. Ethics

In Denmark, the project was registered with the Danish Data Protection Agency, and permission to register patient data without consent from the patients was obtained from the Danish Health and Medicine Authority (3-3013-353/1/1). In The Netherlands, the IRB (Regionale toetsingscommissie patiënt gebonden onderzoek [Regional Evaluation committee for patient research] - Medisch Centrum Leeuwarden [RTPO-MCL]) approved the study and granted a waiver of informed consent (TPO 706).

3. Results

3.1. Pilot testing phase

All participants in the qualitative pilot test had understood all of the items, all considered the questions relevant, and none identified domains or items that were missing. No items were removed, but we made some adjustments to phrasing according to suggestions from the participants, especially for questions about involvement in decision making, and after discussion of these results, 2 questions about the role the families experienced they had and wanted to have had in end-of-life decision making were added. These 2 questions were pilot tested among 4 family member and 10 staff before the validation phase.

3.2. Validation phase

Of the total 110 responses (55 from each country), 37 were from family members of patients who died in the ICU. Participation rate was 87%; for the euroFS-ICU questionnaire only (family members of discharged patients), the rate was 83%, and for the combined euroFS-ICU and euroQODD (family members of patients who died in the ICU), the rate was 95%. Fig. 1 shows participation rates from both countries.

Table 1 provides an overview of background characteristics of participating family members and their relatives (the patients). Because of the ICU differences (regional vs university affiliated), the reasons for

admissions differed between the ICUs, and the Dutch patients had significantly higher SAPS and SOFA scores and a higher percentage of patients being mechanically ventilated.

3.3. Distribution of responses

Table 2 shows main results regarding the quality of care from the euroFS-ICU. The areas getting the lowest scores were connected with symptom management, information (consistency and overall quality), and decision making. Of family members who felt that inclusion in the decision-making process was not good, 11 had answered the question about why. Three felt that they had been included too much (all from Denmark), 7 felt they had not been included enough, and 1 responded “other reasons.”

There was a tendency for family members of patients who died in the ICU to assess quality of care higher than those of patients who survived. There were no significant differences between the 2 groups except for “presence at bedside” ($P = .02$) and “consistency of information” ($P = .02$).

Table 3 presents results from the euroQODD. These items were only completed by family members of patients who died in the ICU and show lower ratings for “comfort on the ventilator” and for “discussion of preferences before and in the ICU” than for other categories.

The median ceiling percentage (the percentage of responses in the highest category for ordinal response scales [“excellent” and “all the time”]) for both measurements was 41% (30%–47%), and the median floor percentage was 0% (0%–1%). Median percentage of missing data for all questions was 0% (0%–1%).

3.4. Content validity and test-retest reliability

For the euroFS-ICU, the median assessments of the questions being relevant and understandable were 98% (96%–99%) and 98% (97%–99%), respectively. For the euroQODD, the median assessments of relevance and understandability were 97% (92%–100%) and 97% (94%–100%), respectively. The average test-retest agreement for the Likert scale responses in the euroFS-ICU was 0.69 (0.53–0.83).

3.5. Construct validity

The median total euroFS-ICU score was 82.9 (69.7–92.1); for family members of discharged patients, 81.9 (65.8–90.8); and for family members of patients who died in the ICU, 86.8 (73.6–92.1) ($P = .37$). The median overall euroQODD score was 90 (80–100).

Table 4 presents correlation analyses. The euroQODD was significantly correlated with the euroFS-ICU. The euroFS-ICU key questions correlated significantly with total score, as did the overall care euroQODD, but the euroQODD key question (end-of-life care according with wishes) did not significantly correlate with overall rating of care.

With limitation of the analyses to include only 1 family member for each patient, results were essentially the same suggesting that the results were not affected by a lack of independence of observations.

A total of 21% of family members had moderate/serious symptoms of anxiety, and 10% had moderate/serious symptoms of depression 3 weeks after ICU discharge or death. Median levels of posttraumatic stress symptoms were 1.3 (0.6–2) for intrusion, 0.6 (0.3–1) for avoidance, and 0.7 (0.2–1.5) for hyperarousal. No significant correlation was found between the overall euroFS-ICU score or the euroQODD score and levels of anxiety, depression, or posttraumatic stress symptoms.

4. Discussion

The present study describes the initial validation of 2 measures adapted for a European context and provides information about both European families' satisfaction with ICU care and their ratings of the quality of dying in the ICU. The total euroFS-ICU score was similar to

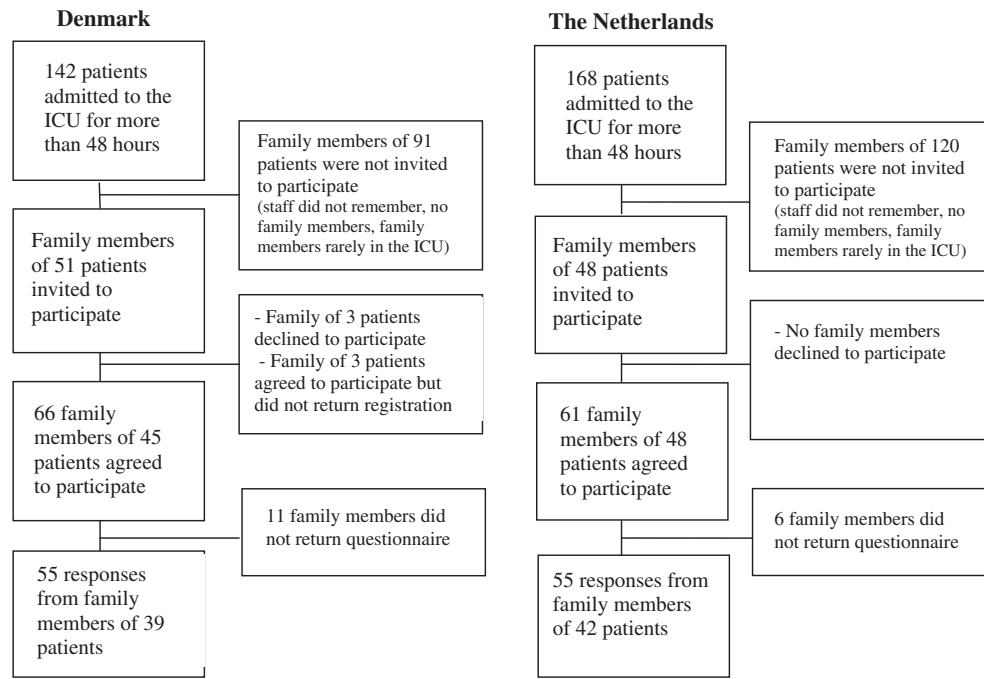


Fig. 1. Flow chart of participants.

prior studies using the FS-ICU [9,19]. The median overall euroQODD care score was higher than in a North American intervention study [19] but similar to the Dutch prestudy [13].

Overall, family members assessed the quality of care fairly high, but there is room for improvement especially regarding symptom

management, information (consistency and overall quality), and the decision-making process. As found in other studies [20], families of discharged patients seemed less satisfied with ICU care and had a tendency to have a higher level of anxiety after the ICU stay compared to families of patients dying in the ICU. This shows that focus on the needs of all family members, not only family of dying patients, is mandatory to improve quality of care and decrease negative impact on post-ICU quality of life.

Questionnaire methodology experts recommend that response scales are balanced with equal positive and negative options [21]. Most of the scales in the FS-ICU range from excellent, very good, good, fair, poor, and not applicable and are, therefore, not balanced [10]. Nonetheless, we kept the 5 category responses because it is the standard response scale in the satisfaction and health status literature and because the “poor” category is rarely chosen. The median floor effect in this study was 0 showing that the poor category was rarely used and the need for a “very poor” category seems low. In addition, very dissatisfied family members have the option of expressing their assessment in the open-ended questions.

The level of ceiling effect (Tables 2 and 3) in both the euroFS-ICU and the euroQODD was similar to other instruments [22,23] but higher than recommended [21]. The high ceiling effect may entail less ability to discriminate and thereby less applicability for detecting improvements of interventions.

The low percentages of missing data in both the euroFS-ICU and the euroQODD support the questionnaire's face and content validity in a European setting. For comparison, 9 items were being left blank in more than 50% of the returned questionnaires when the original QODD was used in a Dutch setting [13]. Likewise, medians of 97% to 98% of questions being assessed as relevant and understandable in both the euroFS-ICU and the euroQODD emphasize a high content and face validity.

Our hypothesized correlations were found between key questions and the total euroFS-ICU score and between the euroFS-ICU and the euroQODD, indicating construct validity. However, this needs to be tested in a larger sample. The lack of significant correlation between overall euroQODD score and end-of-life care according to wishes may be due to the small sample size or the question may not be applicable for testing construct validity. If, for example, the patient's wishes were

Table 1

Background characteristics for participating family members and patients and patient ICU data

| | Denmark | The Netherlands | P ^a |
|---------------------------------|----------------|-----------------|----------------|
| Family | | | |
| Age, mean (SD) | 57 (13) | 52 (14) | .05 |
| Sex, women, n (%) | 30 (55) | 35 (64) | .33 |
| Relation | | | |
| Partner, n (%) | 27 (49) | 21 (38) | .36 |
| Daughter/son, n (%) | 22 (40) | 28 (51) | |
| Other, n (%) | 6 (11) | 6 (11) | |
| Patient | | | |
| Age, median (IQR) | 74 (65–79) | 70 (61–76) | .15 |
| Gender, Women, n (%) | 15 (37) | 16 (38) | .89 |
| Days in ICU, median (IQR) | 7.5 (5.2–15.0) | 6.8 (4.1–10.3) | .14 |
| Level of therapy | | | |
| Full, n (%) | 26 (63) | 27 (64) | .93 |
| Limitations, ^b n (%) | 5 (12) | 6 (14) | |
| Withdrawn, n (%) | 10 (24) | 9 (21) | |
| Discharge | | | |
| Planned, n (%) | 23 (56) | 29 (69) | .02 |
| Dead, n (%) | 11 (27) | 13 (31) | |
| Other, ^c n (%) | 7 (17) | 0 | |
| Reason for admission | | | |
| Respiratory, n (%) | 27 (66) | 9 (21) | <.001 |
| Sepsis, n (%) | 7 (17) | 14 (33) | |
| Cardiovascular, n (%) | 1 (2) | 17 (41) | |
| Other, n (%) | 6 (15) | 2 (5) | |
| Mechanical ventilation, n (%) | 31 (76) | 41 (98) | .003 |
| APACHE II, median (IQR) | 24 (21–32) | 24 (20–33) | .78 |
| SAPS II, median (IQR) | 42 (36–56) | 54 (42–72) | .01 |
| Admission SOFA, median (IQR) | 5 (4–8) | 9 (7–12) | <.001 |
| Highest SOFA, median (IQR) | 7 (5–9) | 10 (8–13) | <.001 |

IQR indicates interquartile range.

^a The Student *t* test, χ^2 /Fisher exact test, or Mann-Whitney *U* test as appropriate.

^b Withholding of life-sustaining therapy, not withdrawal.

^c Transferral to other hospitals or lack of available beds in the ICU.

Table 2
Families' perception of ICU quality of care (euroFS-ICU)^a

| | Family members of | | | | | | | |
|------------------------------|-------------------------------------|-----------|------|--------------------|---------------------------|-----------|------|--------------------|
| | Patients surviving to ICU discharge | | | | Patients dying in the ICU | | | |
| | Excellent | Very good | Good | Other ^b | Excellent | Very good | Good | Other ^b |
| Treatment of patient | | | | | | | | |
| Concern and caring | 58.9 | 32.9 | 8.2 | | 54.1 | 43.2 | 2.7 | |
| Symptom management | | | | | | | | |
| Pain | 41.1 | 35.6 | 17.8 | 4.5 | 56.8 | 27.0 | 10.8 | 5.4 |
| Breathlessness | 38.9 | 30.6 | 22.2 | 8.4 | 46.0 | 37.8 | 2.7 | 13.5 |
| Agitation | 30.1 | 38.4 | 17.8 | 13.7 | 37.8 | 29.7 | 10.8 | 21.8 |
| Treatment of family | | | | | | | | |
| Atmosphere in the ICU | 50.7 | 31.5 | 16.4 | 1.4 | 54.1 | 35.1 | 10.8 | |
| Consideration of needs | 45.8 | 29.2 | 22.2 | 2.8 | 56.8 | 27.0 | 13.5 | 2.7 |
| Emotional support | 35.6 | 31.5 | 23.3 | 9.6 | 51.4 | 29.7 | 13.5 | 5.4 |
| Presence at bedside | 46.6 | 26.0 | 26.0 | 1.4 | 67.6 | 24.3 | 5.4 | 2.7 |
| Information needs | | | | | | | | |
| Ease of getting information | 45.2 | 38.4 | 15.1 | 1.4 | 51.4 | 32.4 | 13.5 | 2.7 |
| Understanding | 42.5 | 35.6 | 17.8 | 4.1 | 51.4 | 29.7 | 13.5 | 5.4 |
| Honesty | 42.5 | 37.0 | 17.8 | 2.7 | 46.0 | 32.4 | 16.2 | 5.4 |
| Completeness. What is done | 41.1 | 35.6 | 12.3 | 11.0 | 51.4 | 18.9 | 21.6 | 8.1 |
| Completeness. Why is it done | 39.7 | 39.7 | 13.7 | 6.9 | 51.4 | 27.0 | 16.2 | 5.4 |
| Consistency | 26.4 | 45.8 | 19.4 | 8.3 | 24.3 | 24.3 | 21.6 | 29.7 |
| Overall quality. Physicians | 28.8 | 45.2 | 17.8 | 8.2 | 32.4 | 40.5 | 18.9 | 8.1 |
| Overall quality. Nurses | 38.4 | 38.4 | 19.2 | 4.1 | 32.4 | 35.1 | 21.6 | 10.8 |
| Decision making | | | | | | | | |
| Inclusion | 24.3 | 28.6 | 27.1 | 20.0 | 43.2 | 21.6 | 24.3 | 10.8 |
| Support | 24.6 | 27.5 | 29.0 | 18.8 | 43.2 | 24.3 | 21.6 | 10.8 |
| Adequate time | Yes | No | D/k | | Yes | No | D/k | |
| | 71.4 | 10.0 | 18.6 | | 75.0 | 11.1 | 13.9 | |

Results are shown as percentages of responses. D/k indicates "don't know."

^a Part 1 in the euroQ2.

^b Covers "fair," "poor," "don't know," and "not applicable."

to die at home, dying in an ICU would not be according to the patient's wishes, but overall rating of care could still be high.

As shown in other studies [6,7,24], a substantial number of family members had symptoms of anxiety and depression and posttraumatic

stress-like symptoms 3 to 5 weeks after ICU death or discharge. Being a family member to an ICU patient makes a substantial impact post-ICU, and this underlines the necessity of ICU care that also takes the needs of families into account. The hypothesized correlation between

Table 3
Families' perception of quality of dying in the ICU (euroQODD)^a

| | Denmark (n = 16) | | | | The Netherlands (n = 21) | | | |
|--------------------------------------|----------------------|------------------------------|----------------------------|--------------|--------------------------|------------------------------|----------------------------|--------------|
| | All ^b | Most | Good bit | Other | All | Most | Good bit | Other |
| Pain under control | 37.5 | 43.8 | 6.3 | 12.5 | 14.3 | 38.1 | 19.1 | 28.6 |
| Comfortable on ventilator | 7.7 | 23.1 | 30.8 | 38.5 | 15.0 | 50.0 | 10.0 | 25.0 |
| Keeping dignity | 18.8 | 43.8 | 18.8 | 18.8 | 19.1 | 33.3 | 4.8 | 42.9 |
| | Yes | Partially^c | No | D/k | Yes | Partially^c | No | D/k |
| Emotional support for patient | 62.5 | 18.8 | 6.3 | 12.5 | 57.1 | 9.5 | 0 | 33.3 |
| Spiritual support for patient | 46.7 | 26.7 | 6.7 | 20.0 | 52.4 | 4.8 | 4.8 | 38.1 |
| Discussed preferences before ICU | 25.0 | - | 56.3 | 18.8 | 28.6 | - | 61.9 | 9.5 |
| Discussed preferences in ICU | 37.5 | - | 25.0 | 37.5 | 23.8 | - | 76.2 | 0 |
| End-of-life care according to wishes | 56.3 | 6.3 | 6.3 | 31.3 | 66.7 | 19.1 | 4.8 | 9.5 |
| Life unnecessarily prolonged | 0 | 0 | 100.0 | 0 | 0 | 4.8 | 85.7 | 9.5 |
| Chance to say goodbye | 81.3 | 6.3 | 0 | 12.5 | 76.2 | 14.3 | 4.8 | 4.8 |
| Overall rating of care (median/IQR) | 9 (8-10) | | | | 9 (9-10) | | | |
| | Strongly | Agreed | Neither^d | Other | Strongly | Agreed | Neither^d | Other |
| Agreed with decision | 53.3 | 13.3 | 20.0 | 13.3 | 57.1 | 28.6 | 9.5 | 4.8 |
| Actual role in decision making | 1^e | 2 | 3 | 4 | 1 | 2 | 3 | 4 |
| Wanted role in decision making | 0 | 61.5 | 38.5 | 0 | 4.8 | 19.1 | 76.2 | 0 |
| | 0 | 15.4 | 84.6 | 0 | 4.8 | 19.1 | 71.4 | 4.8 |

Results are shown as percentages of responses.

^a Part 2 in the euroQ2.

^b Response categories: "all the time," "most of the time," "a good bit of the time," combined other: "some of the time," "a little bit of the time," "none of the time," "don't know," and "not applicable."

^c Where marked with "-", this was not a response option.

^d Neither agreed or disagreed.

^e 1, physicians made the decision without involving family; 2, physicians made decision after discussing it with family; 3, the decision was made jointly between physicians and family; 4, combined other: the family made the decision after information from physician, the family made the decision themselves, don't know.

Table 4

Comparisons of total euroFS-ICU score and overall euroQODD score with key questions and levels of anxiety, depression, and posttraumatic stress symptoms

| | Total score euroFS-ICU | | Overall care euroQODD | |
|--|------------------------|----------------|-----------------------|----------------|
| | Correlation | P ^a | Correlation | P ^a |
| euroFS-ICU | | | | |
| Courtesy, respect, and compassion toward patient | 0.64 | <.001 | | |
| Overall quality of information | | | | |
| Physicians | 0.78 | <.001 | | |
| Nurses | 0.72 | <.001 | | |
| euroQODD | | | | |
| End-of-life care according with wishes | 0.13 | .52 | −0.09 | .64 |
| Total score euroFS-ICU | | | 0.54 | .003 |
| HADS | | | | |
| Anxiety | −0.04 | .65 | −0.32 | .05 |
| Depression | 0.05 | .61 | 0.22 | .20 |
| IES-R | | | | |
| Intrusion | 0.00 | 1.00 | −0.15 | .39 |
| Avoidance | 0.01 | .95 | −0.03 | .86 |
| Hyperarousal | −0.02 | .83 | −0.09 | .61 |

^a Spearman rank correlation coefficient.

experiences of ICU care and level of symptoms was not found in this study, although a study by Azoulay et al [6] found a significant correlation. This may be due to the general high level of satisfaction in this study, post-ICU symptoms of anxiety and depression and posttraumatic stress-like symptoms being influenced by a number of other factors, cultural differences between France and Denmark/The Netherlands, or the relatively small sample sizes in this study.

One of the differences between North America and Europe is the roles that family members play in regard to decision making [25]. In the United States, family members are more likely to be involved in decisions about withholding and withdrawal of life-sustaining treatment. This is less common in most European countries, where physicians are the legal decision makers [25], although there is a movement toward shared decision making in Europe [26]. In the euroQ2, the questions about involvement in decision making, both generally and in connection with end of life, have been those most commented on. Decision-making questions were rephrased to capture the families' experiences and wishes regarding involvement in major decision making without leaving them with the impression that they had responsibility for the decisions themselves.

The strengths of the study included the high response rate, participation of family members from 2 countries, and the adaption based on 2 well-validated North American questionnaires. The study also had several limitations. First, there may be limitations in generalizability. This study was performed in areas where most are wealthy, white, protestant, and well educated. The study was conducted at a single center in each of 2 countries and may not be representative of all Danish and Dutch family members. In addition, our results may not be generalizable to other regions such as Eastern or Southern Europe, and adaptability to other regions will require further study. Second, although almost all family members being asked to participate did so, a substantial number of family members were not asked to participate in the study. When asking ICU staff why families had not been approached, the most common answer was that the staff had forgotten about the study. If this was the main reason, the risk of nonresponders being different from the responders is probably less. If the ICU staff intentionally or unintentionally only invited family members who seemed satisfied, the results would be positively biased. Third, the test-retest was based on 20 participants, which is less than the recommended 50 test-retest participants [27], and the results are, therefore, a preliminary indication of the reliability of the euroQ2. Finally, further psychometric validation including item-response and factor analyses on a larger sample is needed for verification.

5. Conclusion

The euroQ2 (composed of euroFS-ICU and euroQODD) was assessed as relevant and understandable by family of critically ill patients, suggesting high face and content validity. Ceiling effect was high but comparable to similar instruments, the percentage of missing data was low, and test-retest reliability was acceptable. We identified significant correlation with constructs that we hypothesized would be related to the euroFS-ICU and the euroQODD, suggesting construct validity. These findings suggest that these measures are promising for assessment of family satisfaction with care and family ratings of quality of dying in research. Further validation is needed before these measures are ready for use for quality assessment or clinical practice.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <http://dx.doi.org/10.1016/j.jccr.2015.06.004>.

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